Original Article

The development of a self-help intervention to build social confidence in people living with visible skin conditions or scars: a think-aloud study

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Abstract

Introduction: People with a visible difference, such as scarring or a skin condition, can experience anxiety and intrusive reactions from others when in social situations. The use of products to conceal marks on the skin is provided in a number of different hospital services and by charities. However, there are relatively few psychosocial interventions available for these individuals.

Objectives: To examine the views of skin camouflage users and practitioners on the acceptability, usability and need for a specifically developed cognitive behavioural therapy (CBT) self-help booklet.

Methods: A think-aloud protocol and descriptive form of thematic analysis were used to ascertain participants' views of this novel psychosocial intervention. Nine participants took part in think-aloud interviews that were analysed using thematic analysis. Six skin camouflage users and three skin camouflage practitioners participated in the study.

Results: Support for the relevance, acceptability and usability of the booklet was found from both participants who used camouflage and those who provided it. However, some participants reported that they would envisage that some people would need additional support so as to be able to use the techniques described within the booklet.

Conclusions: This study represents an important step towards developing a brief self-help intervention for people with living with visible skin conditions or scars and demonstrates the importance of seeking feedback from experts by experience on theoretically informed psychological interventions for this patient group.

Keywords
Self-help, stigmatisation, scarring, skin conditions, think aloud, qualitative research

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Lay summary

Individuals with visible difference can experience anxiety, depression and decreased quality of life. However, there are relatively few psychosocial interventions available to help improve the lives of individuals with visible difference. This study provides preliminary evidence for the feasibility and usability of a novel psychosocial intervention, designed to improve social confidence and reduce social distress, for individuals with visible difference. Specifically, we sought to examine the views of skin camouflage users and practitioners on the acceptability, usability and need for a specifically developed cognitive behavioural therapy (CBT) self-help booklet. An interview which included a guide to facilitate reflection on the materials was used to ascertain participants' views of our novel psychosocial intervention. Nine participants took part, six skin camouflage users and three skin camouflage practitioners. The participants indicated that the self-help intervention had relevance, acceptability and usability. However, some participants reported that they would envisage that some people might need additional support to be able to use the techniques contained within the booklet. The findings from this study highlights the need for further development and testing of this psychosocial intervention, which holds promise for improving the lives of individuals with visible difference.

People living with visible skin conditions and scars can experience a variety of psychosocial difficulties including anxiety and depression[1] as well as increased levels of appearance specific distress[2,3] that can adversely affect quality of life (QoL).[4,5]

High levels of fear of negative evaluation and social anxiety have been found in people living with a range of conditions that affect appearance.[6–8] Newell and Marks[9] compared responses on a fear questionnaire for people with agoraphobia, social phobia conditions causing a visible difference. They found that people with a visible difference on their face showed similar patterns of avoidance to those with agoraphobia and social phobia. However, distress related to the perceived visibility of the condition is known to be poorly correlated with objectively rated disease severity and psychological variables have been argued to play a more significant role in adjustment.[10]

There are a number of theories that aim to understand the impact of living with a visible difference.[11] For example, Thompson and Kent[12] suggest that shame plays an important role and that the experience of social exclusion can lead people with a visible difference to develop social anxiety specific to their appearance concern. Models such as Kent's[13] posit that the experience of actual or perceived stigmatisation can lead to the development of appearance anxiety that is maintained with the use of avoidance and concealment. Other models have placed emphasis on the cognitive processes associated with overvaluation of appearance that may well be associated with internalisation of cultural stereotypes or pressures.[6,11,13–18]

There is good evidence for the effectiveness of cognitive behavioural therapy techniques (CBT) for the treatment of general social anxiety both when delivered face-to-face and in a self-help format.[19,20] The potential utility of CBT-based interventions as a therapeutic tool for people with appearance altering conditions has been recognised[6] and there has been some limited testing of self-help in this area.[21–23] CBT in this context would aim to alter unhelpful appearance-related schema, challenge anxious thoughts related to negative social evaluation and remove safety behaviours such as subtle forms of concealment. However, such interventions also need to include strategies for managing episodes of actual stigmatisation. Kleve et al.[24] reported upon the evaluation a small number of face-to-face CBT interventions. The intervention included assertiveness and social skills training as well as more typical CBT techniques, in a specialist disfigurement treatment centre and reported positive findings. Bessell et al.[21] have also developed a computer-based intervention for the management of disfigurement-related distress. Nevertheless, reviews indicate that there remain relatively few self-help psychosocial interventions available for people specifically affected by skin conditions or with scarring; with the exception of the Kleve et al.[24] study, almost no evaluations of the effectiveness of face-to-face psychotherapeutic interventions are available in the literature.[25,26] Lavda et al.[25] conducted a meta-analysis that found that the majority of psychological interventions available

for skin conditions were simple behavioural interventions such as habit reversal. Nevertheless, they reported that such interventions showed promise and had a moderate effect on psychosocial outcomes. Further, a number of treatment manuals have been written to guide psychological practitioners; while some of these have been based on extensive research, the interventions themselves have yet to be fully tested.[6]

Investigating the potential benefits of psychological interventions with people specifically seeking camouflage treatment has the potential to provide a valuable opportunity for the development of low-intensity interventions that could be provided alongside camouflage but also be made available in primary mental healthcare and in dermatology clinics.

When developing a complex psychosocial intervention, the Medical Research Council (MRC) recommends the identification of the evidence base and appropriate theory related to the intervention, followed by formal assessment of feasibility and acceptability.[27] Consequently, this study aims to explore the views of skin camouflage users and practitioners on the acceptability, usability and need for a CBT-based self-help booklet focussing on improving social confidence and reducing social distress.

Method

Design

A qualitative think-aloud protocol and semi-structured interview were used to ascertain the views of participants on the acceptability, usability and need for the self-help booklet. The 'think-aloud' technique gives access to the cognitive processes of the person and therefore provides rich verbal data.[28] This technique has been used in previous research developing healthcare interventions.[29–32]

The self-help booklet being evaluated in this study was developed by the first and last author and is based on a theoretical model of social anxiety that has proven to be effective in guiding more intensive interventions.[33] The booklet includes components such as psycho-education, cognitive restructuring and graded exposure,[34] and acknowledges that people with a visible condition may experience actual intrusive reactions from others. The booklet was developed with feedback from providers and users of camouflage (see 'Acknowledgements'). It is available on the British Association of Dermatologists patient support website (www.skinsupport.org.uk).

Procedure

Recruitment. Camouflage users were recruited from a sample of patients who attended an NHS camouflage clinic and through the websites and social media sites of voluntary sector organisations associated with skin camouflage, skin conditions or burns. Ethical approval was obtained via the NHS research ethics approval system.

Participants were eligible to take part in the study if they were aged ⩾ 16 years and currently using skin camouflage with a minimum of two months of continuous use. Participants were excluded if they were unable to participate in an interview in English. Additionally, people whose scars were a result of self-harm were not included, as such participants might be likely to have additional psychological issues that are less likely to be amenable to low-intensity self-help.[35]

The study also sought to recruit a sample of camouflage practitioners. These participants were recruited nationally through a voluntary sector organisation. Potential participants were identified by the charity Changing Faces and an invitation email and information sheet were sent to them.

Data collection. Before the interview date, participants were posted a copy of the self-help booklet. A 'think-aloud' protocol and semi-structured interview were used.[36] During the interview, participants were asked to look through the self-help booklet section by section and speak out loud what they were thinking. Further structured questions on the booklet's content, layout, usability and utility were then asked at the end of each section. A standardised script was used with each participant.

The interviews were all completed face-to-face in the participant's home. Interviews were recorded using an encrypted digital recorder. In order to provide contextual background to the study, participants were asked to complete a set of demographic questions and two measures of psychological distress. Participants completed the Brief Fear of Negative Evaluation scale (BFNE),[37] a 12-item measure assessing a person's concern about the opinions of others, and the World Health Organization Quality of Life Brief Scale (WHOQoL Brief).[38]

The camouflage practitioners took part in the think-aloud interview via telephone interviews that were recorded using an encrypted digital recorder. Recordings of the interviews were transcribed verbatim by an approved transcription

service who had signed a confidentiality agreement or by the first author. All transcripts were audited for accuracy.

Data analysis

The transcribed data were analysed using thematic analysis.[39] In thematic analysis, the data are examined for patterns, which are then defined and organised in order to encode the data.[39,40] The analytic process included the following stages: familiarisation with the data; generation of initial codes; searching for themes; reviewing of themes; and defining and naming themes. This process was followed for each transcript separately and then transcripts were compared, contrasted and combined. NVivo[41] was used to manage the data and facilitate analysis.

Results

Six camouflage users and three camouflage practitioners were recruited. A sample size of 8–10 participants is in line with other studies that have used this methodology to develop health interventions.[29] Table 1 gives a summary of the contextual information collected from camouflage-user participants. Practitioner participants were all women and had been offering skin camouflage services to clients for 1.5–10 years.

Analyses on the views of the camouflage-user participants will be presented first, followed by the findings from the practitioner participants.

Camouflage-user feedback

All of the camouflage users made positive comments that the information and techniques included appeared useful and relevant to them. However, some participants expressed concern that it might not be appropriate for everyone and some had reservations about providing a booklet without having other support available. Nevertheless, the majority described the booklet's content as helpful and relevant to people living with a visible skin condition:

> '*I think the fact that you've got "my physical reactions" could actually provoke thoughts or how I feel or the behaviour, so that in the middle is quite relevant and obviously they all feed into each other don't they.*' P5

All of the camouflage-user participants mentioned activities within the booklet that they viewed as being potentially helpful:

Table 1. Summary of background information from camouflage-user participants.

Demographic	n
Age range (years)	49–72
Gender	
Female	6
Ethnic background	
Asian - Indian	1
White - British	4
White - Other	1
Reason for using camouflage	
Vitiligo	2
Skin condition (unspecified)	1
Birthmark	1
Scar from surgery	2
Length of time using camouflage	
Range	10 months – 40 years
Also a practitioner	2
BFNE score	
Range	14–60 (low–high)
WHOQoL score (higher scores denote better QoL, 100 maximum)	
Domain 1 range (Physical health)	19–100
Domain 2 range (Psychological)	38–94
Domain 3 range (Social relationships)	44–100
Domain 4 range (Environment)	63–100

BFNE, Brief Fear of Negative Evaluation Scale (Leary, 1983); WHOQoL, World Health Organisation Quality of Life – 26 (WHOQOL Group, 1998).

> '*[The thought challenging activity is] extremely important because this is where it tells you exactly what one is thinking and what to do with it.*' P2

The booklet was reported as being understandable and clear. Five of the camouflage-user

participants felt that the booklet was written in a clear and understandable way.

> *'It's very easy to understand.'* P2

Some also made positive comments about the use of examples.

> *'I think this one is clear and I think it's good to have the example here and then have the diagram for them.'* P1

All of the camouflage-user participants described how they thought the booklet could or should be used in practice. Four of the camouflage-user participants stated that the booklet should not be completed without support.

> *'I think when you're talking more about emotional support, you're talking about seeing someone face to face, not a booklet.'* P5

Some participants said that the booklet could be used as a way of broaching the subject of the psychosocial impact with people coming to the skin camouflage clinic.

> *'Give you your options and say "this is what's available to you. What do you think you need?"'* P3

Others reiterated concern that additional support would need to be available within camouflage clinics if such a booklet was to be made available:

> *'You have to remember that the camouflage practitioner is not a psychologist, to me this is something they should almost go to a counsellor.'* P1

Five camouflage-user participants gave suggestions for changes or mentioned aspects that could be improved in the booklet. Three participants suggested that further examples would make some of the tasks clearer.

> *'Maybe an example in each so "my thoughts", "my feelings", "my reactions" and "my behaviours" so someone can see what you're thinking of and they can get on that wavelength.'* P1

Another participant felt the length could be reduced and that the booklet should have a more personal style of writing.

> *'bit less wordy, it's… you're making it, I suppose in a way it has to grab people's attention and be personal I think.'* P5

Five of the participants mentioned concerns about the 'Dealing with comments and reactions from others' section. Participants felt that some of the suggestions could be interpreted as confrontational and therefore should be amended.

> *'you need to get your responses a little bit more so it's giving them non-confrontational humorous ways to say something back.'* P1

Camouflage practitioner feedback

All of the practitioners made positive comments about the self-help booklet.

1.1 *Agree with the booklet's message.* All practitioners agreed with the booklet's message; that people with a visible difference can struggle with social confidence.

> *'You know, they don't feel confident, I think that's a major, major factor and no matter how small the skin condition is.'* C2

All three practitioners said the booklet was generally comprehensible, understandable and clear.

> *'I think it is clear and you've kept it generally quite concise and that's all required I think.'* C2

Overall, all practitioners thought the instructions given for the activities were clear.

> *'I think that's fairly straightforward, I think that would be easy for someone to think "Yes, I think I could put down a couple of points."'* C1

All the practitioners felt that the majority of the information and activities included in the booklet were helpful and useful.

> *'Yes, I think that's a good exercise isn't it, because you've already written it all and you've gone through ticking thinking patterns.'* C2

> 'I like the last paragraph about the eye contact… I think that's really good and also the fact that it's saying you're going to feel as though you're acting, but if you do it for long enough, you'll actually believe it and more importantly, so will other people.' C3

All the practitioners felt that the booklet could fit with skin camouflage services but

expressed a range of ideas about how. For example, whether all clients should be routinely sent a booklet before their appointment or whether it should be offered as an option during the session.

> *'You either send it out to everybody and they come back or you wait until they come to clinic and if you feel that somebody is struggling on that side and you do get that, you can give them the booklet and you can perhaps talk through it with them.'* C2

Although they felt the booklet was a useful tool, all practitioners said they did not think it would be relevant for all the people they see in camouflage clinics. Practitioners felt that the people more likely to use it would be those who are experiencing difficulties and want to build up their coping mechanisms.

> *'Some people, yes. I don't think everybody would want to do it but I think if somebody's really struggling it's good to have.'* C2

Practitioner participants made suggestions for changes to the content of the booklet. For example, two practitioners felt that the introduction moved too quickly between discussing potential difficulties to highlighting stories of people who are coping well.

> *'That little bit is slap bang in the middle of about people who are ok and whether you could bring it out rather than incorporate it … have it separate..?'* C2

Another felt that some of the suggestions in the section on dealing with the reactions of others could come across as confrontational.

> *'I'm not sure I like the bits about "Thank you for staring, it's quite distracting"… I don't know… it's how it might come across… I'd just be worried that it would do the opposite of diffusing the situation…'* C3

All participants suggested that the language used in the booklet could be changed in places.

> *'Paragraphs like predicting the future and mind reading I thought you could perhaps move the emphasis from the negative to the positive.'* C3

A lack of clarity was highlighted within the instructions given for some activities.

> *'I'm a bit confused here, so you write in alternative thoughts one to five, to what? To the above?'* C1

Discussion

The aim of this study was to gain feedback on a CBT-based self-help booklet focusing on improving confidence in social situations. There was a large amount of agreement and shared opinion between camouflage users and practitioners leading to preliminary evidence for the acceptability, usability and need for such a booklet for people with skin conditions or scars. This also supports the potential utility of CBT models of social anxiety[19] for this population. Generally, the information and activities included in the booklet were seen as helpful and appropriate and it was agreed that that the booklet could be a useful tool for at least some skin camouflage users. However, a caveat mentioned by many of the participants was that this type of material would not be relevant for all. A range of changes and improvements were suggested to the length, wording and instructions in order to make the booklet more readable and accessible to camouflage users. Section 5 of the booklet (dealing with comments and reactions from others) was highlighted by a number of participants as an area of concern. Some felt that certain responses could be interpreted as confrontational, suggesting further development and re-working of that section is necessary.

Overall, the participants felt there would be a place for such a booklet within services. The practitioners generally felt that it could be a useful tool within camouflage clinics. Some camouflage users agreed; however, others felt that depending on the level of emotional support needed by an individual, this work might be best completed within mental health services. There was a lack of consensus as to whether such a booklet should be posted to all camouflage clinic attendees as a matter of course, or whether it should be an option provided based on an expression of interest or need.

There are some limitations within our study that require consideration. The camouflage-user sample was purposively selected to be likely to have expert views that would be of use to the development of the intervention, nevertheless they are not fully representative of the population of people living with scars or who have skin conditions. Indeed, views were only obtained from specialist camouflage practitioners and service users, and not from other staff or patient populations where the intervention might be useful (e.g. within a dermatology clinic). Further, it is of particular importance when considering the transferability of our findings to be mindful that all of the participants were women and that none of

them had scars caused by traumatic injury or self-harm. Two participants within the sample had dual status as camouflage practitioners as well as being users of camouflage; while these participants have additional lived experience likely to have been of use in commenting upon the utility of the intervention, they are not representative of first-time users of camouflage services.

The first author was involved in the development of the intervention and also in collecting and analysing the data, and despite participants being encouraged to express criticism of the intervention, this nevertheless represents a risk bias. The intervention itself may have a number of limitations that warrant careful consideration ahead of preparation for further studies. For example, the written format of the intervention will place limitation on its use with certain populations. Clearly, further development of the intervention is needed and should be conducted in line with the MRC complex intervention development guidelines.[27] Further developmental work should also consider the cultural utility of the content intervention. Consequently, further usability and acceptability testing may be needed ahead of deciding whether or to conduct a randomised controlled trial (RCT). A RCT might also seek to investigate whether the intervention is more effective if completed with the guidance of a healthcare professional, as the existing literature on the use of self-help in treating anxiety suggests guided interventions are more likely to be effective[35].

The study suggests that camouflage use might in part be understood within a wider CBT framework of adjustment to visible difference.[6,13] This suggests there is potential benefit in offering CBT-based interventions alongside camouflage services. Other variations of CBT, such as acceptance and commitment therapy, mindfulness-based cognitive behavioural therapy and compassion focused cognitive behavioural therapy, might also be useful to this population and warrant investigation in their own right. Indeed, a recent study indicates that some of the variables specifically targeted in these variations of CBT are associated with appearance-related anxiety in people with burn-related scarring.[42]

This study is the first qualitative examination of the acceptability, usability and need for self-help for people with a skin conditions and scars. The study provides support for the utility of a CBT-based self-help booklet focussed on improving social confidence. Further development, feasibility and piloting work using the self-help intervention is now warranted.

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